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"THIS IS A LIFE ALTERNATIVE YOU CAN TAKE UPON YOURSELF, NO QUESTION ABOUT IT, YOU CAN FIND YOUR JOY AND HAPPINESS IN IT..."

## THE ADOPTION OF CHILDREN WITH SPECIAL NEEDS IN HUNGARY

### 1. INTRODUCTION

This paper has been written with the aim of looking into the problem of families adopting children with special needs. Based on the theoretical foundations of disability studies, the issue to be addressed here pertains to *the characteristics of families opting for the adoption of children with special needs*. Our work has been guided by the paradigm of participative research: one of the researchers has adopted a child with Down Syndrome, while Éva Steinbach, another member of the research team, is a specialist who has taken a key role in supervising the procedure followed during the adoption of children with Down Syndrome.

Our aim is to deepen our understanding of the world of child adopting families, thereby changing the current situation so that in accordance with UN agreements on the rights of children, the highest possible number of children with special needs might be adopted by families rather than be transferred to institutional care. As a consequence of an amendment in 2012 to Act XXXI of 1997, the legislative approach in this country to the general principles on childcare is now in line with international trends by demonstrating preference for family substitution care to institutional care [Child Protection Act, section 7 (2)]. However, children with disabilities do not fall under the purview of this law.

New regulations introduced in accordance with the Act on Child Protection, effective as of January 1<sup>st</sup>, 2014, have reshaped the balance between family care and institutional care, bringing about a shift towards family care. A guiding principle in the new statutory approach is that children under the age of 12 should not be transferred to institutional care; care must be ensured through an adopting family. However, this legal provision does, among other exceptions, not entail mandatory enactment in the case of children with disabilities who can still be transferred to institutional care.

Data – made public in the 2012 Yearbook on Social Statistics, published by the Central Statistical Office, the number of adoptable children, including those in the 'children with disabilities' category, along with adoptions officially approved and the adoptions of children with disabilities – shows that adoption percentages are generally between 35 and 39, i.e. every third child will be adopted by a family. As for children with disabilities, that figure is between 0.5 percent and 2 percent, i.e. *either only one out of fifty or one out of one hundred children will stand a chance of being adopted by*

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a family. The four-year period covered by the statistical information available shows that 39 'disabled children' were given a chance for a better life. It is to be noted that data on the adoption of children with disabilities has been available since 2009 (CSO 2013).

## 2. CHARACTERISTIC FEATURES OF THE ADOPTION OF CHILDREN WITH SPECIAL NEEDS IN THE LIGHT OF RESOURCES AVAILABLE IN HUNGARY

Having already tackled this issue on the basis of foreign literature in an earlier paper (see: Sándor–Horváth 2016), this paper will, therefore, focus on those aspects of the issue which are characteristic of the current situation in Hungary.

The keyword 'adoption' in the data base of university libraries will produce 59 hits, whereas the combination of 'adoption/disabled' will display one hit (Bertók 2011). 'Disability/child protection' will produce one hit on adoptive parents (Kiss 2011). 'Adoption/family/children with Down Syndrome' (Tarró 1999) and 'adoption/physically impaired children' (Győri 2004) will produce one hit each.

It has always been Csilla Bertók's intention not to deal with the notions of 'foster care' and 'adoptive families' separately. Nor does she separate the intention behind adopting children with special needs from the situation when disability becomes an issue following adoption. A significant outcome of a survey based on questionnaires was the finding that characteristically, families who were willing to go through with the adoption procedure had the intention to do so because they already knew the children about to be adopted.

A search performed for the phrase 'disabled/disability and adoption' in the online catalogue of the Metropolitan Ervin Szabó Library produces 15 hits, while phrases containing all of the following words: 'Down Syndrome/physically impaired/deaf and adoption' will produce no hit. The only document to be identified as literature bearing relevance to the topic is an account by Neményi and Takács on discrimination in Hungary regarding adoption. The conclusion drawn by researchers is that only 1 percent of parents who wish to adopt children express willingness to adopt permanently ill or disabled children (Neményi–Takács 2015).

MATARKA (Hungarian Periodicals Table of Contents Data Base), a Hungarian language data base, produces no hit for word pairs containing any of 'disabled/Down syndrome/death/blind/mentally handicapped' alongside 'adoption/available for adoption' for the period between 1800 and 2016. A search for the phrase 'adoption' will produce 26 papers published between 2000 and 2016. Ten of them proved relevant, one of them being a paper by Neményi and Takács. Although one paper tackles the problem of children with Down Syndrome, it contains the findings of a research conducted in France in 2001 (Kibicher 2004). Six other papers tackle the problem of an additional difficulty posed by circumstances in which children with disabilities are to be adopted (Vida 2013), or the danger posed by a lack awareness associated, both nationally and internationally, with the procedural aspects of adoption (Andrási 2009; Bogár 2001; Marschalkó 2013; Neményi 2001), one paper putting forward the idea that it is less difficult for a single parent to adopt a 'sick' child (Kollár 2002).

According to Judit Deli 'the adoption of 65–70 percent of children registered in TEGYESZ (Regional Child Protection Service) as eligible for adoption will in fact go through. In other words, 30–35 percent of these children will be eligible for adoption, but only in a statistical interpretation. Generally speaking, 3–5 percent are either

not healthy or these are children with disabilities whose adoption, in the absence of adoptive parents, can at best be ensured by foster care' (Deli 2006).

The following point was raised by another specialist: 'Would it not be helpful for children not eligible for adoption if, just like in the case of foster care, positive discrimination was used by the government in the form of resources being allocated to families adopting children with disabilities, in order to financially support them? We are sure that many foster parents as well as adoptive parents would be willing to provide a permanent home for children with disabilities' Molnár-Radoszav 2006). We have also come across Zsuzsa Mártonffy's blog on adoption, which featured observations (not meant to be academically in-depth) complete with findings from a 2015 research (Mártonffy 2015).

### 3. RESEARCH AND OUR RESEARCH METHODS

Our research effort focussed exclusively on adoptive parents, foster parents remained outside the scope of our research. Analysis was performed only in connection with parents *who were determined, prior to* the adoption procedure, to adopt children with special needs.

Our research was carried out in four stages: the exploration of

- international and
- Hungarian literature and of the pre-research situation
- questionnaire-based survey and
- narrative interviews.

This paper presents the details of the findings arising from narrative interviews. Narrative interviews constitute the most effective methodology to help interviewees talk about their lives as freely as possible and, by exploiting the fundamental principles of disability studies, are capable of achieving empowerment; by determining the extent to which an interviewee will spell out the details of his/her chosen topic and the manner in which he/she will talk about it, that interviewee will be in full control of the dialogue.

The interview was conducted with the participation of two interviewees (the adoptive mother and adoptive father) and two interviewers (one woman, one man – one of them was an adoptive parent). We are not aware of any similar interview, consisting of four persons, having been conducted elsewhere. Our request made to interviewees to participate in the interviews was accompanied by a letter in which we provided them with information regarding the survey. Between October 2015 and April 2016, a total of sixteen interviews were recorded with the participation of eleven pairs of parents and five mothers. Eleven interviews were held in the home of the adoptive family, one was conducted while the adoptive parent was at work, two interviews were carried out at a different location, while two were conducted in the researchers' office. This paper includes fourteen interviews, two interviews having proved inadequate to fit in with our target group, the reason being that in two instances parents who had gone through the adoption procedure were unaware of the fact that the child to be adopted would be one with disabilities.

The initial question during all interviews was identical: 'Please tell us about your life, tell us what was behind your decision to adopt 'disabled' children?' In the interviews, the word 'disabled' was replaced either by the name of the adopted child or by terms

referred to as a special type of need identified in terms of educational purposes such as 'a child with Down Syndrome', a 'blind' or 'visually impaired child' etc. A type-out containing the recorded interviews was produced by an individual who had previously signed a confidentiality agreement. Following the typing procedure, that very person was obliged to delete both the recorded material from the sound recording device and the written material. The interview tapescripts are approximately 15-20 pages long.

The texts needed to be prepared for analysis. A random check was run to ensure that the recorded interview and the typeout text were identical. This was followed by a procedure during which all materials were rendered anonymous. Events of the interviewees' life were then arranged in a chronological order, i.e. we created a *life version composed of events that had in fact been lived through*, something that in most cases is different from a *narrated version of events that had taken place in an individual's life*, the reason being that interviewees never give a chronological account of their life. Moreover, prior to the start of the analytical process, we discarded all events that took place following adoption as our research was aimed at the decision affecting adoption. In the text, we also separated life events from those other than life events. Finally, we set aside data and mottos from the text of the interview which enabled us to carry out a focussed analysis.

At one stage during the analytical process we used a special technique for narrative analyses originally created by Hernádi (Hernádi 2014) subsequently fine-tuned by Hernádi and Kunt in the course of the current research. By doing so, we used a sequence of accounts given by all interviewers with the aim of creating a common narrative through which the voice of parents could be heard, sometimes bringing forth very similar figures of speech while depicting characteristic, well-defined life events that are known to have built the road to adoption.

## 4. RESEARCH FINDINGS

### 4.1. Narratives constructed via accounts given by adoptive families

'I have no idea where to start. I should start at the beginning, shouldn't I? (I). In fact, without the beginning it will be impossible to understand what happened (E). At this point I should, perhaps, add that when I left school I worked ... for four years in a social institution. My job was to look after new-born babies. There was this little boy whom I grew very fond of. I was thinking of adopting him but I was far too young back then, (I) and it was then that my boss took home a little boy with Down syndrome. As an adoptive parent, I reckon. I was, well, I was surprised and I was glad that there was this opportunity, thinking, well, that was for me, that's what I should do sometime in the future. Then, as years went by (B) I realized I had nothing to be apprehensive about. My first impression was, well, at that young age a child like this was, for me, just like any child in the neighbourhood. The eyes looked a bit Chinese, he had projecting ears, but he was an adorable child (G). Anyway, if I try to explain this in a more subtle manner, my first impression was that when you play ball with them, these children catch the ball just like any other children, they throw it back to you just like those others. So I did something that pleased me, something I like doing. (C) Well, yes, he thinks that's something of a benchmark, if a situation like this comes your way, up your street as it were. (A)... and then, well, I had a

feeling that I had a craving for motherhood. I had made up my mind by then (C) and I told him about my broad idea on this, that I would like to adopt a human being with Down Syndrome... we agreed, though, we both thought that first we should have two biological children, then we would adopt one. (B) Then I was asked if I wanted to adopt a child... if we did, we would only adopt a disabled child... I said it would have to be a disabled child because for some reason no one wants a disabled child... no one would want them. (Ö) Not even four days went by and the phone rang, it was about a child, still in hospital, just born (I). The paperwork wasn't ready yet but they immediately called us, Éva Steinbach telling me that there was this new-born baby. They were expecting us, so could we go and see that child. It happened so fast (N), there was this baby, you see, and she said she just couldn't find a family that would take that baby. What about us, she said, (B) and then, right after that phone call we were on our way to the hospital. We saw the baby (A), they even let us feed the baby... it was so tiny, I was afraid to take it in my hands (G). You have to wait for as long as six weeks, we didn't know how it was gonna shape up, this was a delicate matter, you know. Then the six weeks was over. (B) When we were doing that course they told us, and that was what we saw, too, that when the parents sign the waiver document, that's when the clock starts ticking, six weeks from kick-off. That was a very long time for us. (D). The social inquiry report was done. They had the preliminary psychological examination completed and some, I don't know, some topical thing conversationally or what have you. What we needed to get done was that course, nothing else, really (A). The Ágacska Foundation people are absolutely professional, they really are. All the people in my group had this idea that they wanted to adopt a healthy, perfect child to solve their own emotional problems, get their trauma cured (H). Mind you, it wasn't really about the Down thing there, it was about adoption... healthy kids are different, for these other children it's different again, adoption, even if you tell them about it, they will react differently. Unless they are able to understand, somehow grasp it, OK, great, that's great. Yes, maybe, but I don't really believe this would work out that way. Whereas a healthy child will, if you tell them about it, they will comprehend. Anyhow, you need to tell these other children about it, full stop. How much of it they are capable of taking in is another problem (D). So initially it was family adoption, this is how we had this child with us. As long as we did not have the paperwork on this, almost for a year, the parents were in a position to change their mind (G). A disabled child, well, children like these can benefit from adoption because if they are raised by their natural parents, well, people in the family first have to deal with that situation, a difficult process to get through. But if the parents are determined to go for this option, it means that there will be only acceptance, no parental rejection... you can cope with that. This is a life alternative you can take upon yourself, no question about it, you can find your joy and happiness in it (A). And the child's contribution will be tangible, the feeling of togetherness. The child's share of togetherness. The child needs me as much as I need him or her (F). Anyway, I sort of feel the need to send a message to those who might want to do this adoption thing in the future, 'don't be afraid to adopt babies that are born with an impairment, Down syndrome or whatever else, they are a huge emotional treasure trove' (C).

## 4.2. *The characteristic features and experience of adoptive families*

Interviewees do not associate their child with the condition of being disabled, they do not even use the term except when referring to others talking about such children. Characteristically, their narrative is almost entirely void of any negative connotation being attached to their own child, whereas they give a detailed account of both the physical obstacles that make life difficult for them in their own environment and of the negative attitude of certain individuals. The main reason, however, why a negative frame of mind is alien to the adoptive parents of children with special needs is that due to their experience these people are rendered capable of coping with issues of disability and/or child protection, which they can exploit as a source of energy in dealing with everyday situations and tasks. That experience very often stems from a professional background: several adoptive mothers are (special educational needs) teachers, they work in the social sector or have health-care qualifications. And, although decision-making is the outcome of a joint effort by adoptive couples, it has been confirmed through various life narratives that during a relationship mothers make the final call on the issue of adoption as a result of their professional experience.

Those who have become familiar with the problem of disability, having gained that kind of experience in their own family, have a different set of skills to rely on. In several cases, either one of the parents has a disabled sibling or the adoptive couple has a disabled natural child who was born prior to the adoption. Consequently, disability is not an issue that families need to brace themselves for emotionally either at the start of adoption or at the initial stages of child raising. Having opted for adoption by their own volition, these families accept the fact that children with special needs will become family members not because 'they have been thrust into this situation by a stroke of misfortune.'

At the same time we need to understand that all this is true only of a particular kind of disability, most often the Down Syndrome, of which the adoptive parents were aware when they chose to go for it. In situations when a child has some unexpected impairment or illness, the parents have no alternative but to make their way through the process of acceptance. We had this experience in a specific case when events took an unexpected turn and the parents realized that the child was an autistic. To further complicate an already complex image, in our dealings with some of the parents it was pointed out to us that they decided to adopt a child with disability because either due to their age or to their health condition the chances of having a natural child with disability could not be excluded. Paradoxical as it might seem, we believe that this might not necessarily be the case. What this does suggest, though, is that the situation of a family into which a disabled child is born is substantially different from one which is in a position to choose a particular, acceptable, well-known type of disability. This indicates both the diversity and the elusiveness of the notion of disability as reflected in our mind, while equally associable with specific knowledge acquired in a particular situation. Our interviewees have put an unequivocal interpretation on the health condition of their own adopted child, formulated in a context different from the 'health-illness' or 'ableness-disableness' paradigm.

Based on foreign literature, the assumption seemed realistic that either faith or the fact that people often belong to a religious community were key factors affecting the decision taken by families in showing a willingness for adoption. However, that correlation was not substantiated during our research. The topic of religion was not even mentioned by the majority of parents. An additional group of parents only mentioned it in passing. Not even during feedback did this group indicate that religion

played an important part in their decision to adopt a disabled child. Religion was a dominant part of the interview in only three cases, meanwhile the story of only one interviewee appeared to have a strong motivational value inherent in the religious conversion of that person and the events that ensued. In other families adoption, was the outcome of a decision – possibly arrived at as a result of previous experience or the notion of charitableness and social responsibility – related to the issue of disability and child protection.

It was mentioned earlier on that, unlike in the case of other types of adoption, the primary motivation of parents determined to adopt children with special needs is not driven by the fact that they are a childless couple. However, some of them have, due to infertility or a previous sterilization, taken part in an insemination programme during which they had to endure both the physical and the emotional pain accompanying it. The conclusion, therefore, that our interviewees are representatives of a particular, clearly distinguishable family model, cannot be drawn. Not one element of their openness to adoption can be singled out as a clearly distinguishable force of motivation that accounts for their attitude. These are families with one child, large families, couples and single parents, younger parents and people who decided to adopt a child after their natural, grown-up children left the family nest.

Characteristically, parents who go through with the adoption process with the aim of adopting children with special needs are proud to talk about adoption and will in the short term – certainly in the long term – earn the respect of people both close to them and of those who they are not very closely related to. Children with special needs will not have to face exclusion in the neighbourhood, nor will they be discriminated against in public education or healthcare. Another experience, seen through the eyes of parents, is that their children can have a positive effect on the behavioural aspects of the community.

Based on what we have seen in the context of adoption, in most cases adoptive parents who adopt children through a so-called open adoption procedure, i.e. when the child to be adopted comes from a family, speak positively of that family and see no reason why that family should be blamed for what is happening. Behind this attitude lies the assumption that parents who have decided to put their child up for adoption are doing this because this is how they think they can best serve the interest of that child who, as they understand it, was born with an impairment. Based on what we have seen, parents putting up their child for adoption often have other children being raised in that family. Those parents, therefore, are not unfit for parenthood. What happened is that they in fact could not cope with the impairment of the new-born child. Presumably, they did not have enough support from elsewhere to handle that situation.

Another interesting aspect of the conditions surrounding parents who have decided to put up their child for adoption is that some of them were expecting the baby with a considerable amount of enthusiasm, and these parents were particularly protective of the baby during the pregnancy period. In three cases among those that we have looked into, three babies were born via in vitro fertilization, and it was after the baby's birth that the parents decided to put the baby up for adoption. Social selection, manifested at two separate levels, is a key priority in our disability research. The first level is an initial step aimed at producing perfect babies via the genetic screening of the egg selected for fertilization. Were that process to end in failure, the second step is either intended to culminate in the termination of pregnancy or the initiation of a post-natal adoption procedure rather than the keeping of the baby.

None of the families interviewed regretted their decision to adopt; none of those families would be opposed to a second adoption. Finally, we make a note of the fact



that one of the interviewees was a parent with disabilities. The significance of this lies in the fact that there appears to be scarce knowledge about the subject of adoptive parents with disabilities, whereas in some cases – particularly in situations where the child to be adopted is deaf – the fact that the adoptive parent has had first-hand experience in the context of belonging to a particular culture can be something of an advantage.

## 5. SUMMARY

There is a shortage of information when it comes to research findings regarding the kind of world that adoptive families and adopted children with disabilities live in. In Hungary this subject is tackled mostly by dissertations and informative texts. As for research papers, the emphasis is mainly on child protection or the broader issues of adoption. Consequently, in these papers disability as a phenomenon is only dealt with perfunctorily.

Our paper is comprised of fourteen interviews giving an account of the process of adoption. These interviews provide us with an insight into a diversity of life stories and family models. In the course of our research we became increasingly convinced that all the families which had chosen to go in the direction of child adoption had some kind of previous experience on matters related to disability and child protection. As for the motivation of parents, neither faith nor religion was a definitive driving force behind their actions as these topics were either entirely neglected or were mentioned only in passing by the interviewees. None of the families regretted their decision to adopt. Based on the experience obtained in the process, none of those families would be opposed to a second adoption. Being fully aware of the course of action they were determined to follow, the ramifications of disability are in no way a challenge for them, although they need to deal with the consequences of secondary disabilities or chronic illnesses which were not visible at the time of adoption.

Our research findings seem to underscore the fact that children with special needs belong to a heterogenous group of children whose adoption in Hungary today will be met with difficulties. However, a group of people who do not shrink from the issues accompanying adoption are parents who display a *willingness* to enlarge their family via the option of adopting a child with special needs. All of this seems to justify the argument that recommendations stemming from professional considerations and expert opinion should be put forward so that a much higher percentage of children with special needs might be transferred to the permanent care of adoptive families.



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### Pertinent statutory law

- Act No. LXIV of 1991 pertaining to the announcement of the Agreement made in New York on the rights of the child on November 20<sup>th</sup>, 1989.
- Act No. XCII of 2007 pertaining to the announcement of an agreement on the rights of individuals with disabilities and of the pertinent Optional Protocol.
- Act No CXC of 2011 on national public education
- Decree No. 149/1997. (September 10<sup>th</sup>) on childcare authorities, child protection and childcare procedures.
- Act No. XXXI of 1997 on the protection of children and childcare administration.